HB-6759, Section 4
Testimony by Gayle M. Rigione, Resident of New Canaan, CT
March 1, 2023

To the Co-Chairs, Ranking Members, Vice Chairs and Members of the Education Committee of the State of Connecticut, thank you for this opportunity to address this Committee regarding HB-6759, Section 4, and thank you also for your service on behalf of the citizens of the State of Connecticut.

Personal Background

My name is Gayle Rigione and I am CEO and Co-founder of Allergy Force LLC, a privately-held company dedicated to making food allergic living safer and easier for families with food allergies. I am also a long-time food allergy parent.

My son was born in the late nineties with multiple food allergies. My son's first food allergy diagnosis, at 22 months of age, identified allergies to eggs, peanuts, and tree nuts. Shrimp, soy, and green pea allergies were diagnosed later when he was in pre-school. New allergies to chickpeas and lentils were diagnosed in middle school. Today he still manages allergies to eggs, peanuts, green peas, lentils, and chickpeas. (He remains anaphylactic to eggs and peanuts.)

I am not a medical professional and am testifying as deeply informed parent who works in the food allergy sector.

First, I would like to address HB-6759, Section 4 which says "AN ACT CONCERNING EARLY CHILDHOOD...and (4) allow child care centers to administer epinephrine in emergency situations."

1. Food allergy prevalence is estimated to affect 32 million people in the U.S., approximately 26 million adults (1 in 10) and 6 million (1 in 13) children. According to the American College of Allergies, Asthma & Immunology (https://acaai.org/allergies/allergic-conditions/food/), food allergy symptoms are most common in babies and children, but they can appear at any age. People can develop an allergy to foods they have been eating safely for years.
2. When a child enters an early childhood care/educational setting, he or she may not yet have experienced an allergic reaction to foods, venom, latex, or antibiotics, and therefore may not have a formal diagnosis and a doctor's prescription for epinephrine. Allergic reactions to new foods happen. Bee stings on the playground happen. Latex balloons and toys at class celebrations happen. Allergic reactions from these events are impossible to anticipate because there is no reaction history.
3. The symptoms of anaphylaxis can vary, affecting different body systems at different times during a reaction. A child may present some symptoms, but other telltale signs may be completely missing, or at least missing until they present later during the reaction. For this reason, there may be a delay between staff recognizing an anaphylactic reaction is underway and administering epinephrine. For example, my son never got hives; he coughed, then vomited. Sometimes, though not every time he was exposed to an allergen, his face swelled and he became pale. Once, he felt an overwhelming sense of doom; he was afraid he was going to die.
4. Anaphylaxis can be like a runaway train. As it gains momentum, it's harder to stop. Epinephrine is the first-line treatment for anaphylaxis. The sooner epinephrine is administered, the better the outcome for the child. Multiple doses may be needed.
5. According to the American College of Allergy, Asthma, & Immunology, "If you are uncertain whether a reaction warrants epinephrine, use it right away; the benefits of epinephrine far outweigh the risk that a dose may not have been necessary."

Conclusion: Staff involved in early childhood setting should be legally permitted to administer epinephrine to a child for an anaphylactic emergency, whether or not the child has a formal diagnosis and designated prescription available at the facility. It could mean the difference between life or death for that child.

Secondly, I would like to address implementation of Elijah's Law in Connecticut:

In case you are not familiar with the history of Elijah-Alavi Silvera, I will provide background. Despite Elijah's school having thoroughly documented his severe food allergy to dairy products, an adult employee fed Elijah a grilled cheese sandwich. The school failed to report what he had been fed. Following the incident, despite medical intervention, it was too late to save Elijah and he passed away on November 3, 2017. This occurred in New York City. This child's preventable death deeply saddens the food allergy community to this day and his legacy lives on in the important work of the Elijah-Alavi Foundation.

A state-by-state review of food allergy policies for child care settings was completed in 2022 by the Allergy & Asthma Foundation of America (AAFA), Kids with Food Allergies (a division of AAFA) and The Elijah-Alavi Foundation (Ref: https://www.aafa.org/media/3259/child-care-policies-for-food-allergy-elijahs-law-report.pdf)

The report evaluates states' food allergy policies relative to nine policy standards as follows:

#1 State requires up-to-date health records to include known allergies.
#2 State requires a food allergy care plan for children with food allergies.
#3 State requires child care personnel to receive training for the prevention, recognition, and treatment of allergic reactions to food.
#4 State requires child care personnel to receive training on the administration of epinephrine auto-injectors.
#5 State allows stocking of undesignated epinephrine auto-injectors at child care facilities.
#6 State requires emergency services be contacted immediately whenever epinephrine has been administered.
#7 State requires parent/guardian be notified of possible allergic reaction.
#8 State requires child care facilities to have food service policies that address food allergies.
#9 State requires a child's food allergies to be posted prominently in the child care facility and/or in the food preparation area.

The report found Connecticut to be lacking food allergy policy standards 6 through 9, with standard #5 only partially in place. Let me address the State of Connecticut's shortfalls relative to Elijah's Law more fully:

#5 State allows stocking of undesignated epinephrine auto-injectors at child care facilities.

My understanding is that Connecticut state law permits entities like schools to stock undesignated epinephrine, while OEC regulations prohibit early childhood care/education facilities from stocking undesignated epinephrine for emergency use. Why is stocking undesignated epinephrine treated differently between the public school systems (Pre-K through 12) and early childhood care/education settings? This is potentially a matter of life and death for a vulnerable population under the care of early childhood staff.

This mis-alignment between OEC regulations and our state law needs to be corrected for the reasons I specifically outlined in Points 2-4 in my comments above related to HB-6759, Section 4.

[NB: HB-6333, which is not under consideration by the Education Committee at this time, is "AN ACT CONCERNING THE AVAILABILITY OF EPINEPHRINE IN EARLY CHILDHOOD EDUCATION PROGRAMS. To authorize early childhood education programs to stock and make available epinephrine." Its passage would resolve Point #5's shortfall.]

#6 State requires emergency services be contacted immediately whenever epinephrine has been administered. And, #7 State requires parent/guardian be notified of possible allergic reaction.

Standard operating procedures in most Allergy & Anaphylaxis Emergency Action Plans (completed with a child's healthcare provider) advise calling emergency services, then notifying emergency contacts as soon as epinephrine is administered. According to a detailed article from Allergy & Asthma Network, "You should call 911 because epinephrine wears off within about 30 minutes. You may need another injection or additional treatment and monitoring. Once at the hospital, you may need another dose of epinephrine and epinephrine may be given intravenously [in that setting]." (https://allergyasthmanetwork.org/anaphylaxis/what-is-epinephrine/)

Following are widely available examples of Allergy & Anaphylaxis Emergency Action Plans, all prioritizing calls to emergency services and emergency contacts as soon as epinephrine has been administered:

- **Food Allergy Research & Education (FARE):** https://www.foodallergy.org/living-food-allergies/food-allergy-essentials/food-allergy-anaphylaxis-emergency-care-plan
- **American Academy of Pediatrics (AAP):** https://downloads.aap.org/HC/AAP_Allergy_and_Anaphylaxis_Emergency_Plan.pdf
- **American Academy of Allergy, Asthma, and Immunology (AAAAI):** https://www.aaaai.org/aaaai/media/medialibrary/pdf%20documents/libraries/anaphylaxis-emergency-action-plan.pdf
- **Asthma and Allergy Foundation of America:** https://secure.aafa.org/np/clients/aafa/product.jsp?product=13&

As a food allergy parent, I would expect that the State of Connecticut would want to implement best practice policies to protect one of our most vulnerable populations. Best practice advised by medical professionals is to call *emergency services then notify emergency contacts as soon as epinephrine is administered.*

#8 State requires child care facilities to have food service policies that address food allergies.

A child does not necessarily need to eat a food containing his/her allergen(s) to be exposed to them. For example, when cross contact (CC) occurs, a supposedly safe food is contaminated by allergen-containing food 'residue' usually because of improper handling or improper sanitization of prep areas (E.g., CC occurs when a utensil that has not been properly cleaned after use with an allergen-containing food is re-used for a supposedly 'safe' food; CC occurs when a person preparing food touches an allergen-containing food and then touches an allergy-safe food without washing hands or changing gloves.) Food label reading for allergens is another complicated yet necessary step (and skill) for preventing accidental exposure to food allergens.

Detailed food service policies and procedures can help mitigate the risk of accidental exposures to food allergens in early childhood care/education settings.

#9 State requires a child's food allergies to be posted prominently in the child care facility and/or in the food preparation area.

Clear and consistent communication with staff (including substitute staff) is of critical importance in keeping young children safe from accidental allergen exposures. Posting a child's food allergies in the child care facility and/or in the food preparation area is a means of facilitating such communication among staff responsible for the care of a young child with food allergies.

To my knowledge, Elijah's Law has been implemented in the states of Illinois, New York, and Virginia and is making its way through the legislative process in Pennsylvania and California. As of 2022, The Elijah-Alavi Foundation has

been in discussion with several state representatives in Alaska, Massachusetts, Missouri, New Hampshire, and New Jersey, among others, about the need for Elijah's Law. The goal is to implement Elijah's Law in all 50 states to protect young children with food allergies in early childhood care/education settings.

I thank you for your careful consideration of this proposed food allergy legislation, HB-6759, Section 4. I respectfully request that you support HB-6759, Section 4 and joint forward it to the full House for consideration. Lastly, I respectfully request that the State of Connecticut address the food allergy policy shortcomings as outlined above to protect a vulnerable population in the care of early childhood care/education staff.

Thank you,

Gayle Rigione, Food Allergy Parent and Concerned Connecticut Resident
March 1, 2023